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## The Importance of Special Needs Trusts for Children with Autism

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When my child with ASD and intellectual disability was young, I had no idea what tomorrow would bring, much less what would happen years from now, when I would no longer be there. My son's behaviors were anxiety-provoking enough without me having to lie awake at night thinking about the future. But I did anyway, and I was not alone.

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One thing we can do to ease the anxiety and make sure our children are not only safe and secure but can live the best lives possible after we are gone is to prepare an estate plan that takes our children's special needs into account. Usually this means we need to create a supplemental needs trust, also known as a special needs trust (SNT), for our loved one, in addition to a will. Any share of the parents' estate that is allocated to their special child goes to the SNT, to be spent on the child as the trustee sees fit. Usually, an SNT is not funded until both parents pass away. Until then it is just a piece of paper.

By way of background, a trust is a legal arrangement that allows another person (the trustee) to be in charge of your child's money. A special needs trust is different from a regular trust in that the beneficiary – your child – cannot have any control over the trust assets. How the trust money is spent is completely up to the trustee. Special needs trusts are "discretionary trusts," in that distributions are at the complete discretion of the trustee.

An SNT allows your child to have money when you are gone, and still have the public benefits that they may need. Money in the trust is not counted as their money. Some benefits such as Supplemental Security Income (SSI) require the child to not have more than \$2,000 in their own name. Money in an SNT is not considered to be owned by the child, so with an SNT, the child has both the benefits that they need and extra money to live. Without an SNT, whatever you leave your child is likely to be eaten up by costs that otherwise would have been paid for by the state.

The SNT also ensures that the money will be handled by someone who is capable of managing the money and making sure it is spent the right way.

Appointing a trustee to manage your child's money is one of the most important things you can do, but choosing the trustee for a child's special needs trust can be a difficult decision. The trustee will need to take over for you in terms of managing the child's finances, so if you are appointing a family member, it is best if the person not only loves the child, but also is good with money. An added complication is that you will want to name someone who might actually be around when the time comes, i.e., when both the child's parents have passed away and the trustee takes over. This can be accomplished by naming a contemporary, plus an alternate in the next generation, such as a niece or nephew.

The trustee is in charge of deciding how much money in the trust should be distributed to the child, and how often. In addition, the trustee's duties include overseeing investments, paying bills, keeping accounts, and preparing tax returns. Because the trust is meant to cover your child's lifetime, the job of trustee of a special needs trust could last for decades.

The main considerations when selecting a trustee are picking someone who is trustworthy, will stay involved, will seek help as needed, and can make sometimes difficult decisions. The trustee has a duty to manage the trust in the beneficiary's best interest. The trustee does not need legal or financial expertise but must have good judgment.

If you don't know anyone who meets these qualifications, you can look into hiring an independent trustee. This can be an individual or an institution, such as a bank or trust company, a professional trustee, an investment advisor or manager, an investment advisor, an accountant, or a lawyer. In addition to being independent, a professional trustee will usually have experience and expertise in managing trusts. If you aren't comfortable with having a stranger manage the trust, you may want to choose a family member and a professional trustee as co-trustees. The downside to hiring an independent trustee is that the trustee will charge a fee, which is usually a percentage of the trust, but this is generally well worth the benefits that a professional trustee provides.

If your child is a minor, or is over age 18 but not competent, you also will need to name a guardian for the child in your will. I am often asked whether the trustee and the guardian should be the same person. You can do that and make it easier for the guardian to access the money your child needs without having to ask someone else for the funds. Alternatively, you can pick someone else: for example, one family member is more nurturing and can be the guardian, and the other more financially savvy and can be the trustee. Or you may want to keep both sides of the family involved, so you name the mother's relative as the trustee, and the father's relative as the guardian, or vice versa.

Whomever you choose as trustee, it is important to reevaluate your choice every few years. The person who is right today may not be right tomorrow. Your attorney can help you determine who is the best trustee for you.

How much money the parents need to leave to the special child is different in every case. If you don't have what you think is enough, consider purchasing life insurance to fund the trust. A second-to-die (also known as a survivorship) policy often works well in these situations and is less expensive than a regular life insurance policy because the policy doesn't pay out until both parents pass away. A good insurance broker should be able to advise you about your options.

My son is now 30 years old. His behaviors are much better and usually he is a calm, happy young man. The estate plan with a special needs trust that we put in place 10 years ago is still our plan today, and my husband and I know that we have done what we can to make sure our son will have what he needs once we are gone. It may feel like one more thing to add to our already jam-packed life, but it is worth it for the protection it will provide your child in the years to come.



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